PANS/PANDAS Fact Sheet 2015

PANS and PANDAS Defined

A diagnosis of PANS (or PANDAS) means a child has had a sudden, acute onset in multiple neuropsychiatric domains and the trigger is derived from a misdirected autoimmune response to streptococcus or other bacterial, viral, environmental or immune dysfunction. It is a clinical diagnosis and a diagnosis of exclusion.

PANS (Pediatric Acute Neuropsychiatric Syndrome) experts convened in 2012 to further clarify a working criteria derived from the previously identified PANDAS syndrome. PANDAS is a subset of PANS when the trigger is known to be streptococcus. [1]

Diagnostic Criteria: Abrupt, dramatic onset of OCD or severely restricted food intake; symptoms not better explained by a known neurologic or medical disorder; with 2 or more **similarly severe** accompanying symptoms:

- Anxiety
- Emotional lability and/or depression
- Irritability, aggression and/or severely oppositional behaviors
- Behavioral (and/or developmental) regression
- Deterioration in school performance
- Sensory or motor abnormalities
- Somatic signs including sleep disturbances

PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Bacteria) is an acronym identified in 1990's by a team of researchers at the NIMH.
Defined by 5 criteria: 1. Abrupt, significant onset of OCD and/or Tics 2. Includes other neuropsychiatric symptoms 3. Prepubertal onset 4. Association with streptococcal infection 5. Symptoms follow relapsing-remitting course.

What causes PANS (PANDAS)? New and evolving research has begun to substantiate that this syndrome involves a misdirected autoimmune process that affects or weakens the blood brain barrier. The region of the brain primarily affected is the basal ganglia. These are a group of structures that act as "switching stations" in the deepest inner region of the brain. Some of the brain function area managed via the basal ganglia include: movement, cognitive perception, habit, executive "logic based" thinking, emotions and the endocrine system.

Who gets PANS (PANDAS)? Research indicates the vast majority of children are between four and twelve years old although there are outliers that occur on either side of the age range.

PANDAS Network Survey 700 parent anecdotal report (2012)

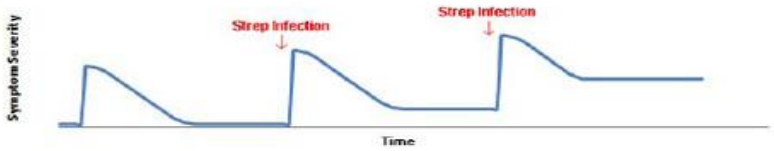
AGE OF ONSET	
• 1 to 3 years	11%
• 4 to 9 years	69%
• 10 to 13 years	19%
• 14+ years	1%

PREDOMINANT SYMPTOM	
• OCD	37%
• TICS	14%
• BOTH	49%

INFECTIONS REPORTED	
• Strep	81%
• Other (Mycoplasma, Lyme, unknown)	19%

[1] Chang, Kiki, et al: Clinical Evaluation of Youth with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS): Recommendations from the 2013 PANS Consensus Conference. JCAP Vol.25, No. 1:, 3-13, Feb. 2015

What is the course of the illness? Exacerbations relapse and remit. They tend to increase in duration and intensity with each episode. Untreated PANS (PANDAS) can cause permanent debilitation and in some cases can become encephalitic in nature. Subsequent episodes can be caused by other environmental and infectious triggers different from the original infection. Treated in a timely fashion – PANS (PANDAS) can remit entirely.



What testing/treatment is available for PANS (PANDAS)?

At the minimum during an initial onset, cases require:

- Throat swab to rule out strep on a 48 hour culture.
- Blood work: streptozyme, ASO and anti-dnase B
- Tests to rule out other infections based upon medical history intake
- Use the PANS Survey at each appointment to measure severity and duration of symptoms

Evolving research indicates that tonsil and adenoid surgery may be extremely important to consider. Referrals to other specialties must be made on an urgent basis.

The longer a child has been ill, discernment of the autoimmune causation is difficult. Evaluations based on the Consensus Statement[1] and the Pandas Physicians Network (www.ppn.org) must be considered. Additional recommendations include:

- Antibiotics with a beta-lactam course to treat infection.
- Follow up with patient to see if remission occurred. Consider continued antibiotic or prophylaxis.
- In severe cases intravenous immunoglobulin (IVIG) or plasmapheresis.
- Residual OCD often benefits from CBT or counseling.

What can be done for the struggling family?

Doctors often wonder if this syndrome is really "only ocd" or "only tic" disorders. The type of **profound change in the child and effect on their family** goes far beyond a simple ocd or tic diagnosis. The family and child are often traumatized, frightened, and the sense of urgency is palpable. Until brain imaging equipment and immune testing improves, it is asked that doctors **at the minimum follow up with the child every three to six months** and observe the course of the child's episodes over time. Refer the family to counselors who can assist with PTSD, sleepless nights and be sure there is support for the struggling siblings. Be sure caregivers are given a respite. Healing can occur.

For Families and Support go to www.pandasnetwork.org
For Practitioners go to www.pandasppn.org
General Information and Advice: www.nimh.nih.gov (search PANDAS or PANS)
Or the International OCD Foundation www.iocdf.org (search PANDAS or PANS)